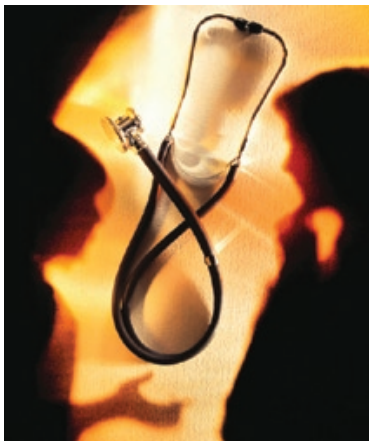
News and Resources from the National Institutes of Health

Kidney Disease Research Updates

National Kidney and Urologic Diseases Information Clearinghouse Winter 2009

NIDDK Report Highlights Rising CKD in United States

A 30 percent increase in chronic kidney disease (CKD) over the past decade has prompted the U.S. Renal Data System (USRDS) to issue for the first time a separate report documenting the magnitude of the disease, which affects an estimated 27 million Americans and accounts for more than 24 percent of Medicare costs. The USRDS is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH).



A major finding of *The USRDS 2008 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease* is that those with CKD are more likely to die from cardiovascular disease than to reach end-stage renal disease (ESRD). Cardiovascular risk factors, however, can be detected and treated, suggesting those transitioning from CKD to ESRD merit more attention. Expenditures during the transition from CKD to ESRD are considerable, ranging from $14,500 for Medicare patients to $29,000 for those covered by employer group health plans in the month of dialysis initiation.

Using data from multiple sources, the USRDS published the report as a handbook for researchers, Government officials, health program planners, and others to develop research goals, assess public health needs, set program priorities, and inform policymakers and the public. USRDS research depends on collaborations with other agencies of the U.S. Department of Health and Human Services, especially the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, and the Centers for Disease Control and Prevention. Patient registries for other countries also contribute data for analyses.

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NIDDK
National Institute of Diabetes and Digestive and Kidney Diseases

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"These latest data on kidney disease underscore the importance of the research we fund," said NIDDK Director Griffin P. Rodgers, M.D., M.A.C.P. "With rising rates of chronic and end-stage kidney disease, we need to stimulate research that will help us discover new, effective therapies for these devastating disorders."

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Director, NIDDK

Disease Burden

Volume One of the report defines the disease burden of CKD and examines cardiovascular and other related health problems, rates of adverse health events, preventive care, prescription medication therapies, delivery of care in the transition to ESRD, and the cost to Medicare and employer group health plans.

Volume Two reports that the number of people with ESRD is increasing in size and cost. The incidence of CKD in 2006 was more than 100,000, or 360 per 1 million people, an increase of 3.4 percent since 2005. More than half a million people had ESRD in 2006. Of these people, 70 percent were on dialysis.

Volume Two also explains that in 2006, Medicare paid about $70,000 per dialysis patient. Medicare recipients with ESRD accounted for a little more than 1 percent of the Medicare population and more than 7 percent of program costs. The total cost for ESRD was $33.6 billion. This number includes Medicare spending and all expenditures by other payers, such as employer group health plans.

"NIDDK's annual analysis and publication of data on kidney disease in the United States is essential in quantifying public health trends, guiding funding priorities, and designing targeted kidney research programs," said former NIH Director Elias A. Zerhouni, M.D. "The major focus on chronic kidney disease in this year's report acknowledges that this disorder is a growing public health issue deserving of wider public awareness and intensified scientific investigation."

The USRDS report is available online at *www.usrds.org*. For more information about kidney disease, visit the NIDDK's National Kidney and Urologic Diseases Information Clearinghouse at *www.kidney.niddk.nih.gov*. ■

Kidney Disease
Research Updates

NKUDIC
www.kidney.niddk.nih.gov

Kidney Disease Research Updates, an email newsletter, is sent to subscribers by the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). The newsletter features news about kidney disease, special events, patient and professional meetings, and new publications available from the NKUDIC and other organizations.

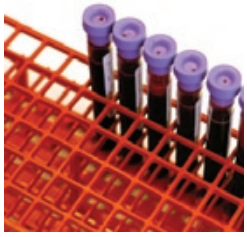
If you would like to subscribe, go to *http://catalog.niddk.nih.gov/newsletter.cfm*. You can read or download a PDF version of the newsletter at *www.kidney.niddk.nih.gov/about/newsletter.htm*.

Executive Editor: Andrew S. Narva, M.D., F.A.C.P.

Dr. Narva is the director of the National Kidney Disease Education Program (NKDEP) within the National Institute of Diabetes and Digestive and Kidney Diseases. Prior to joining the NKDEP in 2006, he served as chief clinical consultant for nephrology and director of the Kidney Disease Program for the Indian Health Service. He has served as a member of the medical review board of ESRD Network 15, as a member of the steering committee of the National Kidney Foundation Kidney Early Evaluation Program (KEEP), and on the Kidney Disease Outcomes Quality Initiative (KDOQI) Diabetes and Chronic Kidney Disease Workgroup.

Larger Labs Report Kidney Function Routinely

Laboratories that conduct the highest number of routine blood tests are more likely than others to report estimated glomerular filtration rate (eGFR), an important measure of kidney function that can identify early kidney disease, according to a survey by the National Kidney Disease Education Program (NKDEP), part of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Results of the survey were reported in the October issue of the *American Journal of Kidney Diseases*.



"Estimated GFR is an important measure of kidney function that can be easily calculated using serum creatinine and a patient's age, gender, and ethnicity."

Andrew S. Narva, M.D., F.A.C.P.
Director, NKDEP

The survey found that more than 86 percent of the highest-volume independent labs—those in the top 5 percent—and more than 55 percent of all labs in the top quarter of high-volume labs report eGFR when the measurement of serum creatinine is ordered. In contrast, only 24 percent of low-volume labs—those in the bottom quarter—report eGFR. The survey shows room for improvement in making eGFR readily available to primary care providers who could be treating early chronic kidney disease (CKD)—primarily caused by diabetes and high blood pressure—and possibly reducing their patients' risk for kidney failure.

"We are encouraged to find that many labs are routinely reporting eGFR, allowing earlier diagnosis and treatment of kidney disease," said former NIH Director Elias A. Zerhouni, M.D. "But the survey illustrates the need to continue NIH efforts to promote automatic reporting of eGFR by all labs so that more people can benefit from earlier diagnosis."

While eGFR reporting is high among high-volume labs, reporting is relatively low—38 percent overall. Reporting by labs in physicians' offices and low-volume independent labs is particularly low, at 26 and 39 percent, respectively. On the positive side, the survey found that about 67 percent of labs that report eGFR do so routinely, without providers needing to ask for the result.

Positive Sign

"Estimated GFR is an important measure of kidney function that can be easily calculated using serum creatinine and a patient's age, gender, and ethnicity," said Andrew S. Narva, M.D., F.A.C.P., director of the NKDEP. "It's a good sign that the highest-volume labs are commonly reporting eGFR. We hope that lower-volume labs will follow their lead, as increased reporting may result in earlier identification and treatment of chronic kidney disease."

Serum creatinine is a waste product in the blood created by the normal breakdown of muscle cells during activity. To learn more about guidelines for estimating and reporting GFR and its importance in detecting and treating CKD, visit the NKDEP website at *www.nkdep.nih.gov*. ■

Measurement of Kidney Function in Children Improved

A widely used formula to estimate kidney function in children with chronic kidney disease (CKD) has been revised to make it more precise, according to a study published on January 21 in the online edition of the *Journal of the American Society of Nephrology*. The study is based on data collected by the Chronic Kidney Disease in Children (CKiD) clinical study—the largest prospective cohort study of CKD in children in North America. CKiD is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH).

"This study illustrates the importance of our commitment to research on chronic kidney disease in children."

Griffin P. Rodgers, M.D., M.A.C.P.
Director, NIDDK

"This study illustrates the importance of our commitment to research on chronic kidney disease in children," said NIDDK Director Griffin P. Rodgers, M.D, M.A.C.P. "As NIDDK-supported research discovers more accurate methods of diagnosing and monitoring biomedical conditions, our ability to treat those conditions, reduce suffering, and prolong life also continues to improve."

Glomerular filtration rate (GFR), the flow rate of fluid through the tiny capillaries in the kidneys called glomeruli that filter waste materials out of the blood and into the urinary system, is the most useful indicator of kidney function. Measuring GFR, however, is costly, time-consuming, and difficult to perform at regular clinical office visits. As a result, different methods of estimating GFR using biochemical markers of kidney function have been developed.

Schwartz Formula

One of the methods for estimating GFR, the Schwartz formula, estimates GFR from an equation that uses serum creatinine—a waste product in the blood—and height. GFR estimates by this formula have been used as one of the enrollment criteria for the CKiD study, which assesses children with mild to moderate CKD.

The current study, led by George Schwartz, M.D., a professor in the Department of Pediatrics at the University of Rochester who originated the formula in the mid-1970s, used data from baseline CKiD visits of 349 children ages 1 to 16 to evaluate the existing GFR prediction equations.

The investigators compared the Schwartz formula with the current gold standard iohexol clearance method of determining true GFR, which measures the rate of disappearance of the x-ray dye iohexol from the blood, and found the Schwartz formula overestimated GFR. Because the iohexol method is only used every 2 years after the first two visits in the CKiD study, an accurate assessment of GFR is needed during the intervening annual visits.

After comparing various estimated GFR (eGFR) models using a testing data set of 168 children in the CKiD study, investigators found that a modified Schwartz formula using height, serum creatinine, cystatin C—a small protein expressed throughout the body—blood urea nitrogen, and biological sex came the closest to replicating the results of the iohexol method.

Use of eGFR allows investigators to describe the trajectory of declining kidney function and to adjust the dose of medications so they don't become toxic to the kidneys. However, the investigators also point out that the revised formula may not be useful in the general pediatric population because the children they studied have reduced growth rates and delayed puberty.

"The relationship between estimated GFR and the biochemical markers may be different

Measurement of Kidney Function, continued on page 5

Zerhouni Ends Tenure as NIH Director

Deputy Director Kington Steps in as Acting Director

Elias A. Zerhouni, M.D., a physician-scientist and world-renowned leader in radiology research, ended his tenure as director of the National Institutes of Health (NIH). From May 2002 through October 2008, Zerhouni led the agency through a challenging period that required innovative solutions to transform basic and clinical research into tangible benefits for patients and their families.

"I have had the privilege of leading one of the greatest institutions in the world for six-and-a-half years."

Elias A. Zerhouni, M.D.

Zerhouni plans to pursue writing projects and explore other professional opportunities.

"I have had the privilege of leading one of the greatest institutions in the world for six-and-a-half years," Zerhouni said. "NIH's strength comes from the extraordinary commitment and excellence of its people in serving a noble mission. It also comes from the nation's scientific community, whose discoveries alleviate the suffering of patients throughout the world."

NIH Roadmap

The hallmark of Zerhouni's tenure is the NIH Roadmap for Medical Research, launched in 2003 after extensive consultations with the scientific community. The NIH Roadmap brought together the NIH's 27 Institutes and Centers to fund compelling research initiatives that could have a major impact on science but that no single Institute could tackle alone.

Reaching out to the Public

Under Zerhouni's leadership, the NIH reached out to the public in an unprecedented way with the communication of science-based health information and scientific results. He led efforts to make the incomparable resources of the NIH and its grantees accessible to the public. Key to these efforts are the health education programs across the agency, including the development of materials for people who have literacy, language, or access barriers.

The NIH is part of the U.S. Department of Health and Human Services and is the nation's premiere biomedical research agency. The agency has more than 18,000 employees and a fiscal year 2008 budget of $29.5 billion. It supports more than 325,000 research personnel at more than 3,100 institutions throughout the United States and around the world.

Raynard S. Kington, M.D., Ph.D., NIH deputy director under Zerhouni, will serve as acting director until a permanent director is appointed by President Obama. ■

Measurement of Kidney Function, from page 4

in this population than in a population with more normal kidney function and without poor skeletal growth," said Schwartz. "Although we did not observe that our formula changed with puberty, other populations with more normal physique and health status should be examined to evaluate the estimated GFR for adolescents."

Additional funding for the CKiD clinical study is provided by the NIH National Institute of Neurological Disorders and Stroke, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and the National Heart, Lung, and Blood Institute.

More information about the CKiD study is available at *www.ClinicalTrials.gov.*

The National Kidney and Urologic Diseases Information Clearinghouse offers fact sheets about kidney disease in children at *http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases.* ■

Medicare Legislation Contains Kidney Education Package

Pilot Projects and Medicare Benefits for Kidney Education Included

Medicare legislation passed into law July 15, 2008, authorizes more extensive coverage for preventive health services, including two initiatives aimed at promoting kidney disease education.

The Medicare Improvement for Patients and Providers Act (MIPPA) authorizes pilot programs in three states to increase public awareness of chronic kidney disease (CKD), promote screening for CKD, and provide surveillance of CKD prevalence. The three state programs will be selected and established this year.

In 2010, MIPPA will also make people on Medicare with Stage 4 CKD eligible to receive individualized kidney education training from a qualified health care provider. Medicare will cover the training fee. Medicare officials are consulting with health care providers, health educators, and other stakeholders to establish rules governing this new benefit.

People with Stage 4 CKD face an important decision about their treatment should they progress to Stage 5, also called kidney failure, and require dialysis or a kidney transplant. Making an informed decision requires knowledge of available treatment options and potential complications.

MIPPA's main thrust is to adjust Medicare payment schedules and some eligibility rules. For example, MIPPA blocks a scheduled 10.6 percent reduction in what doctors receive for outpatient services. MIPPA also increases assets patients can keep and still qualify for the Medicare Savings Program—from $4,000 to $6,000 for individuals, and from $6,000 to $9,000 for couples.

For more information about CKD, visit *www.kidney.niddk.nih.gov.* ■

NKDEP Targets Health Disparities

The National Kidney Disease Education Program (NKDEP) explored strategies to eliminate health disparities in chronic kidney disease (CKD) at its annual Coordinating Panel meeting on October 25 at the National Institutes of Health. The panel cited collaborations among health care providers, community outreach efforts, and educational materials as key to addressing health disparities.

"If we could merely reduce the excess incidence of ESRD among minority communities to equal that of the Caucasian population, that alone would reduce the annual ESRD budget by $10 billion a year."

Keith Norris, M.D.
Director, Clinical Research Center, Charles Drew University of Medicine and Science

Health disparities are differences in clinical outcomes based on race/ethnicity, sex, age, religion, or other factors. The NKDEP's mission is to reduce the burden of kidney disease by educating health care providers and the public about kidney disease.

"There are tremendous disparities in kidney disease at all stages," said NKDEP Director Andrew S. Narva, M.D., F.A.C.P. "If our program is not successfully addressing these disparities, we're really not doing our job."

CKD, which afflicts an estimated 27 million Americans, disproportionately affects minorities. Compared with Caucasians, minorities have a higher prevalence of end-stage renal disease (ESRD), said Keith Norris, M.D., director of the clinical research center at the Charles Drew University of Medicine and Science. African Americans are four times more likely than Caucasians to have ESRD.

While genetic differences may account for some disparities, Norris said, race/ethnicity in CKD is more a surrogate of socioeconomic status than a biologic determinant. He suggested public health efforts that increase awareness and improve access to care stand to significantly reduce CKD among at-risk populations.

CKD is becoming more prevalent, increasing 30 percent over the past decade, and treatment is costly. Renal replacement therapy, including dialysis and kidney transplantation, represents about 6 percent of Medicare's budget. "If we could merely reduce the excess incidence of ESRD among minority communities to equal that of the Caucasian population, that alone would reduce the annual ESRD budget by $10 billion a year," Norris said.

The NKDEP Coordinating Panel is a volunteer group of CKD clinicians, public health workers, and advocates. Panelists at the meeting shared their challenges and successes at preventing and managing CKD to help the NKDEP generate ideas for addressing health disparities.

Collaborative Practices

Collaborative practices, such as the El Rio Community Health Care Center, can improve care for underserved populations with chronic conditions like CKD, according to Marisa Soto-Rowen, Pharm.D., C.D.E, of the Association of Clinicians for the Underserved, an El Rio pharmacist and a member of the NKDEP's Coordinating Panel. Based in Tucson, AZ, El Rio has embraced a program that taps the expertise of clinical pharmacists to coordinate care for patients with diabetes, hypertension, and dyslipidemia—all of which are risk factors for CKD.

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El Rio serves roughly 70,000 patients, including Pascua Yaqui tribal members. Its patient population is predominantly low-income, with high prevalences of diabetes, cardiovascular disease, and CKD.

With initial funding from the Office of Pharmacy Affairs, a part of the U.S. Department of Health and Human Services, the program efficiently tracks treatment interventions and outcomes, facilitates dialogue between primary care providers and nephrologists, and educates clinical pharmacists and pharmacy students about the need to monitor patients' renal function and other chronic disease risk factors. By transitioning to electronic medical records, the program encourages patient-driven scheduling, which makes better use of clinic time.

CKD education materials from the NKDEP are available at *www.nkdep.nih.gov.*

With the NKDEP's help, the program has persuaded the clinical laboratory at El Rio to routinely report estimated glomerular filtration rate (eGFR), a practice helpful for identifying early CKD. "Through the help of the NKDEP and Dr. Narva, we really pushed our lab to report eGFR," said Soto-Rowen.

Community Outreach

Janice Lea, M.D., associate professor of medicine at Emory University, highlighted the 2003 NKDEP pilot program "You Have the Power to Prevent Kidney Disease," which assessed CKD awareness among health care providers and the public both before and after an education intervention.

According to an initial survey taken before the intervention, fewer than 50 percent of respondents knew that being African American or having a family history of kidney disease were risk factors for CKD. Lea urged more community outreach efforts like the NKDEP pilot program but with more extensive follow-up to measure their effectiveness. "These education efforts are great, but we need metrics to measure how effective they are."

Education Materials

Panelists, including Jeanne Charleston, R.N., director of Research Clinical Operations at the Johns Hopkins University, offered praise for the NKDEP's new "Explaining GFR" tear-off pad, which was designed to help health care providers explain to their patients how well their kidneys are working, based on eGFR results, and what to do to keep their kidneys healthy. Each tear-off pad has 50 sheets providing key concepts and talking points.

Charleston, who is involved in the Chronic Renal Insufficiency Cohort Study, said people weren't getting the message that they had CKD. "We are just not doing as good a job of telling people they have kidney disease," said Charleston.

Furthermore, said Charleston, primary care physicians are unclear about what to do when eGFR results suggest CKD. Instead of taking action to prevent disease progression, they take a "wait and see" approach. Charleston suggested the NKDEP expand the use of visual elements in their education materials—as was done in the "Explaining GFR" tear-off pad—to better connect with at-risk populations.

To read the full summary report of the NKDEP Coordinating Panel meeting, go to *www.nkdep.nih.gov/about/10252008-CP-meeting-notes.htm.*

CKD education materials from the NKDEP are available at *www.nkdep.nih.gov.* ■

Featured in the NIDDK Reference Collection

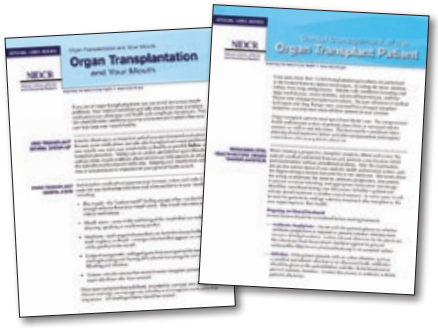
Cooking and Kidney Disease

Brilliant Eats: Simple and Delicious Recipes for Anyone Who Wants to Be KidneyWise offers easy, delicious, and nutritious recipes for anyone who is interested in overall kidney nutrition. Author Kelly L. Welsh, R.D., C.D., writes, "Although every person with kidney disease needs an individualized diet, there are several nutrients that all renal diets consider: calcium and phosphorus, sodium, fluids, potassium, protein, and calories." The book begins with general nutrition guidelines, and then offers specific information for patients who are predialysis, on hemodialysis, on peritoneal dialysis, or who have undergone a kidney transplant. The cookbook presents recipes organized into five sections: appetizers, salads, sides, entrees, and desserts. Each recipe includes the preparation time, number of servings, ingredients, preparation instructions, and nutritional information per serving, including calories, protein, carbohydrates, dietary fiber, fats, phosphorus, potassium, and sodium. The book concludes with a reference section that offers a subject index, a refrigeration chart, a list of baking equivalents, garnishes, herbs, and a few lined pages for notes. The book is illustrated with brightly colored graphics and full-color photographs. The cookbook, copyright 2008, is published by the PKD Foundation and is available for $24.95. All proceeds support the PKD Foundation. To order a copy, contact CAM Inc., 9221 Flint, Overland Park, KS 66214, 1–866–524–6732, 913–381–7139 (fax), *pkd@cam-inc.com.* Online ordering is available at *www.kidneywise.org.*

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Reference Collection is a free, online database that helps health care professionals, health educators, patients, and the general public find educational materials not typically referenced in most databases. The NIDDK does not control or endorse the information contained in this collection; the information is provided as a convenience to our visitors. To find more resources about kidney disease, visit *www.catalog.niddk.nih.gov/resources.*

Additional Resources

Kidney Transplantation and Oral Health



Organ transplant patients are at increased risk for serious oral health problems and need specialized dental care. The National Institute of Dental and Craniofacial Research offers two new fact sheets to educate patients and dentists about how to manage and prevent oral complications related to organ transplantation.

Dental Management of the Organ Transplant Patient, for dentists, presents the challenges in treating pre- and post-transplant patients and offers strategies for providing care.

Organ Transplantation and Your Mouth, for patients, discusses how transplantation and anti-rejection medications affect oral health and the steps to take before and after transplantation to keep the mouth healthy.

To order free copies of these publications, contact the National Oral Health Information Clearinghouse at *nidcrinfo@mail.nih.gov,* 301–402–7364, or go online to *www.nidcr.nih.gov.*

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Featured Website

Children and Clinical Studies

A new website developed by the National Institutes of Health informs parents and health care providers about clinical studies for children. Featuring video interviews with researchers, parents, and children involved in clinical trials, the website addresses why research on children is important, factors to consider when deciding whether to enroll in a clinical trial, and the challenges and benefits of participating. To visit the site, go to *www.childrenandclinicalstudies.nhlbi.nih.gov*.

Updated Publications

The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) has updated the following publications:

- *Anemia in Kidney Disease and Dialysis*
- *Diabetes Insipidus*
- *Eat Right to Feel Right on Hemodialysis*
- *Growth Failure in Children with Kidney Disease*
- *Hemolytic Uremic Syndrome in Children*
- *Renal Tubular Acidosis*

NKUDIC publications are available at *www.kidney.niddk.nih.gov*. ■

Upcoming Meetings, Workshops, and Conferences

The National Institute of Diabetes and Digestive and Kidney Diseases Information Clearinghouses will be exhibiting at the following upcoming events:

American College of Physicians Internal Medicine 2009

April 23–25 in Philadelphia.
For more information, go to *www.acponline.org/meetings/internal_medicine/2009/attendees/?pr13r*.

American Urological Association Annual Meeting

April 25–30 in Chicago.
For more information, go to *www.aua2009.org*.

American Nephrology Nurses Association 40th National Symposium

April 26–29 in San Diego.
For more information, go to *www.annanurse.org*.

American Academy of Physician Assistants Annual Conference

May 23–28 in San Diego.
For more information, go to *www.aapa.org/annual-conf/sandiego09/index.php*.

American Diabetes Association 69th Scientific Sessions

June 5–9 in New Orleans.
For more information, go to *http://professional.diabetes.org/Congress_Display.aspx?TYP=9&CID=57909*.

American Academy of Nurse Practitioners 24th National Conference

June 17–21 in Nashville, TN.
For more information, go to *www.aanp.org/AANPCMS2/Conferences*.

American Association of Diabetes Educators 36th Annual Meeting and Exhibition

August 5–8 in Atlanta.
For more information, go to *www.diabeteseducator.org/ProfessionalResources/AnnualMeeting*. ■

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